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Review Article

Online Training and Support Programs Designed to Improve Mental Health and Reduce Burden Among Caregivers of People With Dementia: A Systematic Review



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ABSTRACT

Keywords:
Dementia
Internet-based interventions
technology
caregiving
mental health

Introduction: Dementia poses a considerable socioeconomic burden to society. On a global scale, family and other unpaid care predominates. Supporting caregivers is crucial, but scalable interventions are currently lacking. Because a growing number of studies have suggested that online training and support programs hold considerable promise for scaling up, we reviewed existing literature.

Methods: We systematically searched 6 databases to identify studies of Internet-based interventions designed to train and support caregivers of people with dementia, and we formally assessed risk of bias. Our prespecified primary outcomes of interest included both mental health and caregiver burden/perceived stress. Our secondary outcomes of interest included knowledge, quality of life of caregivers, quality of care, caregiver response to challenging behaviors, coping, and self-efficacy.

Results: Eight randomized control trials met our inclusion criteria involving over 900 participants. The content and structure of Internet-based interventions, outcome measures, and duration differed markedly, and selection, performance, and reporting biases were varied and on occasion of concern. Six studies reported outcomes in caregivers' mental health outcomes, 3 studies reported burden outcomes. Three studies reported knowledge skills, quality of life and reaction to challenging behaviours, whereas 2 studies reported changes in coping outcomes and self-efficacy. No studies reported outcomes on quality of care.

Discussion: Although there is some evidence that Internet-based interventions can improve mental health outcomes for informal caregivers of people with dementia, marked methodological diversity across studies prevented the robust pooling of the results. A concerted and cohesive approach from all stakeholders is now required to help realize the full potential of this emerging field.

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Currently, 47 million individuals have dementia and this figure is projected to rise to 131 million by 2050.¹ Dementia is the main predictor of disability and need of care in older adults² who are often cared for by family members and other unpaid (informal) caregivers, particularly in low- and middle-income countries.^{1,3} The prevalence of psychological distress, such as depressive and anxiety symptoms, is high in caregivers of people with dementia.^{3,4}

Training and support for family and other unpaid caregivers is an important public health priority for which urgent global action is required. The strategy and action plan on ageing and health of the

World Health Organization (WHO) states that special efforts are needed to ensure that caregivers have access to information and/or training they need to perform their role. This will warrant the provision of the best possible care and relieve caregivers of the stress that arises from being insufficiently informed and skilled on how to deal with challenging situations.⁵ Further, at the 2017 World Health Assembly the global action plan on dementia was approved by WHO's 194 Member States and specifically stated a need for Internet and mobile phone technologies to provide, "education, skills training, and social support."⁶

While different types of support for caregivers exist, healthcare providers need to be able to make informed choices about which modality provides optimal use of available resources. For example, with better understanding of the caregiving experience, caregiver support interventions have, in recent decades, evolved from informal self-help/support groups to more formalized interventions that include psychoeducational foci, case management, and individual and family therapy as well as on-line support. Face-to-face interventions providing information, training and support can contribute to improve the quality of care and reduce the psychological distress it poses on caregivers worldwide.^{7–10} However, face-to-face interventions are often resource intense, with respect to human resources and finances. Therefore, they are not scalable in lower resourced settings, while training of family and other unpaid carers is urgently needed. Because of lack of transportation or respite care, living in remote locations, or reluctance to join a group, face-to-face interventions may not be accessible to all caregivers, thus, creating a need for evidence-based alternatives. To scale up caregiver training and support programs at a global level at a much faster speed than currently is the case, the use of the Internet-based interventions seems to have great potential.¹¹

Online training and support programs may have several advantages when compared with face-to-face interventions. From the perspective of caregivers, such interventions have considerable potential to reach many caregivers in remote areas alongside those who are time poor and cannot leave a person with dementia unattended or are undertaking other numerous daily activities such as housework, employment, or looking after additional family members.¹² Further, online interventions also have potential to reduce stigma by eliminating the need to visit a mental health institution. From the perspective of healthcare providers, the reduced need for trained coaches or therapists (even where a coach is still part of the online intervention) is a universal advantage because in lower income settings such professionals are lacking, and in higher income country settings, socioeconomic pressures favor sustainable models of delivery.¹³

There are many recent reviews that echo the plausibility of the approach, where online training and support programs for family caregivers of people with dementia have been suggested to reduce caregivers' psychological distress, improve mental health, and provide cost-effectiveness.^{14,15} Despite such results, global scaling up, which requires a robust body of evidence before recommendation can take place, has remained elusive. Previous reviews in this field^{16–19} have documented only a few published randomized control trial (RCT) studies including favorable outcomes across a range of outcomes and are of mixed methodological quality. These reviews have also highlighted substantial questions as to how best to deliver such interventions (eg, optimal content, underlying theory model, course intensity).

As this evidence base of studies of online interventions for caregivers of people with dementia continues to increase, a systematic evaluation of current literature would provide a vantage point to collate the current body of evidence and would also provide a much needed opportunity to formally explore the potential sources of heterogeneity of results across published studies.

Therefore, we designed and conducted a systematic review of RCTs of online training and support programs for family and other unpaid caregivers of people with dementia. In addition, we formally assessed the risk of bias and critically appraised other potential sources of heterogeneity of results with a view to informing public health bodies of what the current stage of such interventions is and what the next steps should be to reaching widespread implementation.

Methods

We planned to conduct a systematic review and meta-analysis of Internet-based interventions for caregivers of individuals with dementia using a number of key search terms. We aimed to use meta-analysis to explore the effectiveness of the reported studies and to also appraise individual and overall study quality. Throughout the search process, we followed the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) reporting guidelines.²⁰ We registered the systematic search on PROSPERO (http://www.crd.york.ac.uk/prospero/display_record.asp?ID=CRD42016049102).

Search Strategy

We conducted the search in September 2016 with search terms were based around our participants, interventions, comparators, and outcomes of interest. We included all years, and there were no language restrictions. We searched 6 online databases to identify relevant studies: PubMed, Cochrane library, Cinahl database, ISI web of Science, PsycINFO, and EMBASE. The following search terms were included ("Internet" [MeSH] OR "online" [TIAB] OR "electronic" [TIAB] OR "tech*" [TIAB] OR "e-health" [TIAB] OR "ehealth" [TIAB] OR "m-health" [TIAB] OR "mhealth" [TIAB] OR "telecomputing" [TIAB]) AND ("intervention*" [TIAB] OR "program*" [TIAB] OR "therap*" [TIAB] OR "psycho-education*" [TIAB] OR "psychoeducation*" [TIAB] OR "training" [TIAB] OR "support" [TIAB] OR "Cognitive Therapy" [MeSH] OR "psychological" [TIAB]) AND ("Dementia" [Mesh] OR "Alzheimer disease" [Mesh] OR "MCI" [TIAB]) AND ("caregivers" [MeSH] OR "family" [MeSH] OR "family" [TIAB] OR "friend*" [TIAB] OR "acquaintance*" [TIAB] OR "neighbour*" [TIAB] OR "neighbor*" [TIAB]).

Additional searches were performed on the following trial registers: clinicaltrials.gov in the United States; International Standard Randomised Controlled Trial Number and National Research Register in the United Kingdom; University hospital Medical Information Network- Clinical Trials Registry in Japan; Australian New Zealand Clinical Trials Registry in Australia and New Zealand; the WHO International Clinical Trials Registry Platform; the International Federation of Pharmaceutical Manufacturers and Associations Clinical Trials Portal and controlled-trials.com.

Eligibility Criteria

We focused on Internet-based interventions, which meant that DVD programs or telephone support services for caregivers were not included. All study designs were included for the systematic search, however, only RCT designs would be taken forward for summaries and meta-analyses. Should it not be possible to undertake a meta-analysis we planned to summarize the results of all the available RCT studies identified from our systematic search.

Outcomes

The outcomes of interest included 2 primary outcomes: mental health (depressive and anxiety symptoms) and burden and 6 secondary outcomes: caregiver knowledge, quality of life of caregivers, quality of care, responding to challenging behavior, coping, and

self-efficacy. For burden we included measures of self-reported burden and provided another group summarizing stress outcomes.

Quality of Included Studies

We assessed the risk of bias of the included studies across the domains and using the judging criteria recommended by the Cochrane Collaboration.²¹ If meta-analysis were feasible, we planned to use the Grading of Recommendations, Assessment, Development, and Evaluations (GRADE) scoring system to evaluate each outcome measure of interest across measures of study quality, consistency, directness of findings, and effect size.²²

Results

Our systematic search identified 1508 publications, of which 261 were duplicates leaving an initial screening list of 1247 publications (Figure 1). After 2 blinded reviewers screened these we identified 31 publications, which reported trials of interventions in the field, of which 8 were randomized control trials. The 8 randomized controlled trials included Computerlink,²³ Caregivers friend,²⁴ Caring for Others,²⁵

iCare,²⁶ Ginkgo,²⁷ Mastery over Dementia,^{28,29} Diapason,³⁰ and Star E-learning.³¹ Details of the included RCT studies are reported in Table 1.

Description of the Online Training and Support Programs

The training and support programs differed in their overall content, underlying theoretical model and psychological techniques used, components, and intensity of delivery.

Content

Only one-half of the programs are described in enough detail to understand which themes are part of it. This holds for Mastery over Dementia,^{28,29} Diapason,³⁰ Star E-learning,³¹ and iCare.²⁶ These programs cover more or less the same themes: understanding dementia,^{26,28,30,31} improving communication skills,^{26,28,30,31} arranging help and support,^{26,28,30} coping with caregiver distress,^{26,28,30,31} dealing with functional loss,^{30,31} dealing with challenging behaviors,^{26,28,30,31} and preparation for the future.^{26,30} Although the other programs studied a better understanding of dementia,^{23–25,27} there is not enough information provided to understand other themes that might have been covered.

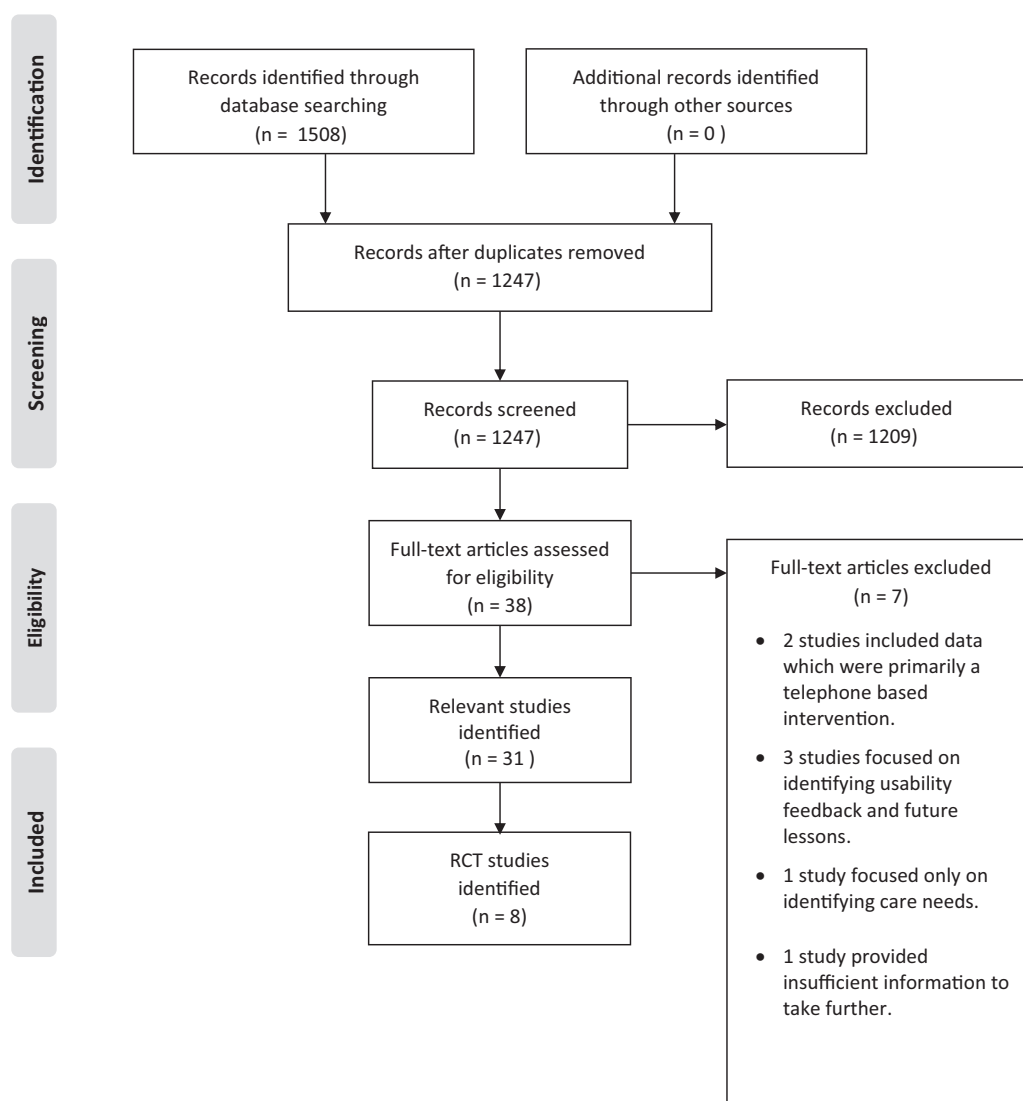


Fig. 1. Preferred Reporting Items for Systematic Review and Meta-analyses (PRISMA) flow diagram. Figure depicts the 1508 publications initially identified of which 261 were duplicates leaving an initial screening list of 1247 publications. After 2 blinded reviewers screened these, we identified 31 publications which reported trials of Internet-based interventions for caregivers of people with dementia, of which 8 were randomized control trials.

Table 1
Details of RCTs Included

Study/Year	Population (Country)	Intervention	Comparison (s)	Outcomes	Findings
Beauchamp et al 2005	Employed family caregivers of people with dementia (USA)	Caregivers Friend: 6 mo access to online intervention with 30 d follow-up (N = 150).	Control: Usual care and waitlist control (N = 149).	Primary; There was no clear single primary outcome stated, however there were eight outcomes of interest which included the use of the following scales; (i) Depression (CES-D), (ii) the State–Trait Anxiety Inventory, (iii) the Caregiver Strain scale from Benjamin Rose, and (iv) Positive Aspects of Caregiving. Instruments were also used to assess stress, self-efficacy and coping skills.	Improvements; Significant improvements in; depression, anxiety, stress, caregiver strain, caregiver gain, self-efficacy, and intention to seek help. No improvement; Ways of coping.
Blom et al 2015	Caregivers of people with dementia (The Netherlands)	Mastery over Dementia: a package of 8 online lessons (1 session per wk) and a “booster” session over a maximum period of 3 mo) (n = 151).	Control: Minimal intervention e-bulletins (n = 100).	Primary: Depression (CES-D) Secondary; Anxiety (HADS-A).	Improvements; Moderate improvement for anxiety, and small improvement for depression.
Brennan et al 1995	Caregivers of people with Alzheimer disease (USA)	ComputerLink a computer network to provide information, communication and decision support delivered over a 12-mo period. (N = 51).	Treatment as usual and ‘placebo’ training where participants were trained to find local services and resources (n = 51).	Primary; There were three separate outcomes of main interest; (i) decision confidence, (ii) decision-making skill and (iii) isolation. Note: Two “intervening” variables were also of interest which included depression and burden.	Improvements; Improved decision making confidence. No improvement; No effect on decision making skills, no improvements in social isolation.
Cristancho-Lacroix et al 2015	Informal caregivers of people with Alzheimer disease (France)	Diapason: A web-based psychoeducational program delivered over a 3-mo period (N = 25).	Control: Usual care (N = 24).	Primary; Caregivers’ perceived stress (PSS-14, primary outcome) Secondary; Self efficacy measured by (RSCS), caregiver bother (RMBPC), burden (Zarit), Depression (BDI-II), coping and self-perceived health (NHP). Note: Measured during face-to-face on-site visits: at baseline, at the end of the program (mo 3), and at follow-up (mo 6).	Improvements; Knowledge of disease as measured through visual analogue scale. No improvement; There were no observed benefits for outcomes regarding stress, burden, self-efficacy, caregiver bother, depression, coping or self-perceived health.
Hattink et al 2015	Dementia caregivers (both laypeople and professionals with subgroup results presented) (United Kingdom and The Netherlands)	Web-Based STAR E-Learning course; an 8 module course given across 2–4 mo (N = 27 for laypeople group).	Control: Waitlist control (N = 32 for laypeople group).	Primary; user friendliness, usefulness, knowledge, attitudes, and approaches of caregivers regarding dementia. Secondary; empathy, quality of life (2 specific questions), burden (1 question), and caregivers’ sense of competence (SSCQ).	Improvements; positive outcomes regarding user friendliness, usefulness; both the experimental and the control group increased in attitude score. Significant improvements were found in treatment group regarding aspects of empathy. No improvement; There was a reduction in the self-reported sense of competence within the treatment group. No improvement in knowledge, quality of life empathy or burden.

(continued on next page)

Table 1 (continued)

Study/Year	Population (Country)	Intervention	Comparison (s)	Outcomes	Findings
Kajiyama et al 2013	Dementia family caregivers (USA)	iCARE: Stress management eTraining program delivered over a 3-mo period (N = 75).	Control: Education only (N = 75).	Primary: Self report measures of stress through the Perceived Stress scale (PSS). Secondary: Caregiver bother (RMBPC), depression (CES-D), and life quality (PQOL)	Improvements; Overall stress. No improvement; No improvement in conditional bother, depressive symptoms and perceived quality of life.
Lai et al 2013	Family caregivers (Hong Kong)	Pilot study of Ginkgo: 7 wk online training workshop with support forum (N = 3).	Control: Onsite, face-to-face group (N = 8).	Primary: No specific primary outcome. Outcomes included the Alzheimer Disease Knowledge Test, Depression (CES-D), Zarit burden, GHQ-30, Quality of life (WHO Quality of Life Measure—brief Version).	Improvements; Between group difference included an improved knowledge for the online group. No improvement; No improvements in depression, burden wellbeing or quality of life.
Marziali and Donahue 2006	Older adults with neurodegenerative disease with Alzheimer disease subgroup (Canada)	Pilot study of Caring for Others: 10-session, manual-guided psychosocial support video conference group, followed by 12 additional online sessions facilitated by a group member, 6-mo follow-up (group with Alzheimer disease, N = 22).	Control: Nonintervention control group (N = 22).	Primary: No specific primary outcome stated. Outcomes of interest included health-status (Health Status Questionnaire 12), stress-response measures (IADL/ADL), depression (CES-D) and caregiver bother (RMBPC) at baseline and 6-month follow-up and the Multidimensional Scale of Perceived Social Support.	Improvements; Secondary analysis indicated a decline in stress, alongside good adherence to the online group discussion themes similar to face-to-face intervention. No improvement: Across all outcomes, there were no differences between intervention and control groups at follow-up.

BDI, Beck Depression Inventory; CES-D, Center for Epidemiologic Studies–Depression Scale; GHQ-30, General Health Questionnaire-30; HADS, Hospital Anxiety and Depression Scale; IADL/ADL, Instrumental Activities of Daily Living; NHP, Nottingham Health Profile; PQOL, Perceived quality of life; PSS, Perceived Stress Scale; RMBPC, The Revised Memory and Behavior Problems Checklist; RSCS, Revised Scale for Caregiving Self-Efficacy; SSCQ, Short Sense of Competence Questionnaire; ZBI, Zarit Burden Interview.

Table describes the study, year, population, comparison, and narrative findings across all RCTs identified.

Underlying theoretical model and psychological techniques

Most programs are based on a stress model, although the exact models vary.^{24,26,28,30,31} The techniques used in the different programs as far as described, include: psychoeducation,^{23–28,30,31} behavioral analysis^{26,28} relaxation,^{26,28,30} behavioral activation,^{26,28} cognitive reframing^{26,28} and improvement of communication skills, also to ask for help^{26,28,31} problem-solving/decision-making skills,^{23,25,28} and time-management.²⁸ For 1 program, only a very general description is available, including caregiver knowledge, cognitive and behavioral skills and affective learning,²⁴ and for three programs a detailed description of the techniques that are integrated in the programs is lacking.^{25,27,31}

Components

Different ways of delivery were used in the programs:

- Written text.^{23–28,30,31}
- Videos, (interactive) exercises and tests.^{26,28,31}
- A forum,^{23,27,28} video-conferencing²⁵ [Although there was a forum included in the Mastery over Dementia program studied by Blom et al (2015) its use was not included in the study].
- Built in links to Facebook and LinkedIn communities.³¹

Personalization

There were different ways in which the programs were personalized. In 3 of the programs a therapist/psychologist, nurse or peer caregiver was involved.^{23,25,28} In Mastery over Dementia, the coach (therapist/psychologist) provided feedback on homework that was sent after each lesson by each caregiver.²⁸ In ComputerLink, a nurse

monitored daily private email and a public bulletin board, and answered individual questions that were sent by the caregivers.²³ Caring for Others was personalized because of the format of video-conferencing. In some other programs, a tool was used to allocate the content of the program to an individual caregiver.^{23,24,31} In iCare, caregivers were asked to make an individual plan after each lesson.²⁶

The intensity of the 7–12 sessions or lessons varied from 1 to 1.5 hours per week to no time constraints.^{25,27,28,30,31} In some programs, the access to the next lesson was only unblocked once the previous one was entirely viewed,³⁰ or when the coach had sent feedback on the homework and the caregiver had at least opened it.²⁸ The ComputerLink program had 24/7 access,²³ whereas for the intervention based on video-conferencing everyone had to be available at the same moment.²⁵ However, more detailed information on the intensity of the use is not provided, apart from Mastery over Dementia where participants' intensity was maintained by automatic reminders to start a new lesson or to submit homework if they were not active for a fixed period of time.²⁸

Risk of Bias of Included Studies

The overall risk of bias within the published RCT literature was varied; and for many items the risk of bias was unclear due to the lack of detail in reported studies. Where data were sufficient for further comment, performance bias (ie, blinding of participants and personnel) was commonly at a high-risk level, and the potential of attrition bias (ie, incomplete outcome data) were high throughout the majority of studies. Detection bias (ie, blinding of outcome assessment) and reporting bias (selective reporting) were both of

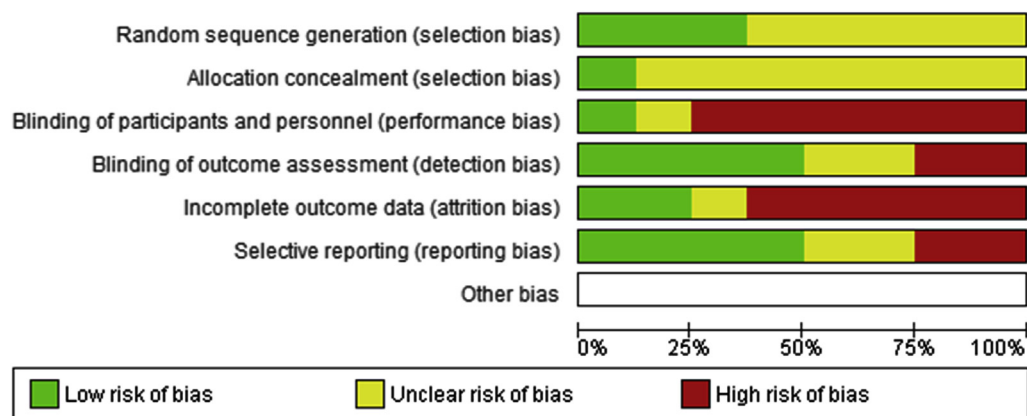


Fig. 2. Risk of bias graph. Graph describes the overall quality of included studies using the Cochrane risk of bias tool. Individual study quality items include random sequence generation, allocation concealment, blinding of participants, and personal blinding of outcome assessment, incomplete outcome data, and selective reporting.

particularly mixed quality across all studies, whereas the risk of selection bias (both random sequence generation and allocation concealment) was low in all studies where the measure was reported in sufficient detail for assessment (Figure 2).

Data Synthesis and Summary of Evidence Identified

Six studies^{24–28,30} reported outcomes regarding caregivers' depression, and two studies found an improvement for this outcome.^{24,28} Two studies^{24,28} reported outcomes on anxiety where both observed overall improvements. Three studies specifically reported “burden” as an outcome^{27,30,31} where there was no specific improvement of burden. In one of the studies a significant negative effect on sense of competence was found which items are highly overlapping with the Zarit burden interview.³¹ Three studies^{24,26,30} reported stress outcomes where two studies reported benefits in the treatment group.^{24,26} A meta-analysis could not be conducted for the primary outcome measures because of the marked methodological diversity and statistical heterogeneity across studies, and, thus, we were not able to undertake GRADE recommendation scoring.

Three papers^{27,30,31} described outcomes regarding knowledge skills, where two studies showed significant improvements.^{27,30} Two studies reported coping outcomes, where there was no improvement in either study,^{24,30} and three studies reported on the quality of life of caregivers where there were no improvements observed.^{26,27,31} Three papers^{25,26,30} described reaction to challenging behaviors, where there were no significant improvements observed. Two studies reported self-efficacy outcomes^{24,30} where one paper demonstrated improvements.²⁴ There were no reported outcomes regarding quality of care.

Discussion

We set out to update current understanding and to explore overall estimates of effect for online training and support programs for informal caregivers of people with dementia. While a meta-analysis was not feasible due to considerable methodological heterogeneity, our search identified 8 RCT studies and, thus, provides the greatest number of studies in the field collated to date. Identified studies were extremely varied in their design including content delivered (eg, mechanism of delivery and overall content), underlying theoretical model and intensity of the course delivered. Where commonalities exist between interventions (for example most psychological techniques were based around stress models), the precise approach was still considerably varied. Insufficient reporting of study details and quality was a problem identified throughout published literature.

Our systematic evaluation of current evidence did not permit us to undertake meta-analysis: falling into the classic “apples and oranges” scenario and parallels findings from other reviews in recent years.^{16–19} Whenever the field reaches the point where we can combine such studies, there is another pertinent challenge to future meta-analysis in that the pre-post estimation of effectiveness of individual studies will often differ in magnitude from postestimation of effects. For example, all anxiety and depression outcomes identified in this review demonstrated treatment groups which were nonsignificantly worse than control at baseline.^{24,26,28,30} The implication of this is that conventional meta-analysis guided by post-measurement may effectively “undersell” the effectiveness of these interventions: yet pre-post estimation of effects may appear to “oversell.” Careful consideration is required.

While we have endeavored to undertake this work as robustly as possible, there are some notable limitations. We carefully considered our definition of “Internet-based interventions” but technology interventions are becoming increasingly complex including TV stations, telephone support, and, thus, there are many studies which we decided a priori would fall outside the scope of this review. Such challenges to review designs are becoming more common³² and as with all systematic review work, it is plausible that we may have missed relevant literature. There are also crucial elements of intervention design, on which we are unable to comment: the reliability of the intervention (eg, device used, internet connectivity) which can be a common issue in dementia technology trials³³ and is an essential consideration to generalizability of findings. Lastly, the breadth of work undertaken in the field of online interventions for caregivers of people with dementia is substantial. Through the course of this work we identified 23 non-RCT studies where studies were also extremely varied in their approach, modality, and outcomes of interest (References given in [Supplementary Appendix 1](#)), but it was not within our objectives to explore these studies in detail.

Similar to other reviews of technology use in dementia,^{17,33} the study quality of individual studies was relatively mixed, and there remain specific challenges to study designs in the field, including potential risks posed by nonblinding of participants, incomplete data reporting, high dropout rates, and recruitment. Such limitations are also true of face-to-face interventions; while there is no “pharmacologic placebo,” which can be offered to participants,³⁴ there may still be an option to deliver the intervention in a more limited information format. Knowledge that an individual is not in a treatment group can be problematic as participants may feel they are “missing out” on a potentially effective intervention. High dropout rates in technology trials are common,³³ but the reasons for this are not entirely well understood and further research is needed to explore this.

These issues, alongside the challenges of recruiting caregivers who are already time poor, means that widespread use and compliance may not be straight-forward.

Given the fast moving pace of this research area, a cohesive and continued reporting of previous and ongoing studies would be considerably advantageous; both to those working at the public health level alongside those embarking on new studies in the area. One real challenge of systematic reviews, is that by the time they reach publication they can be already out of date,³⁵ and this holds particularly true for technology based reviews. One pragmatic solution could be the development of an online repository for sharing previous and ongoing studies. Fittingly, collating evidence on online interventions for caregivers of people with dementia could take advantage of the latest technologies, including machine learning approaches³⁶ whereby much of future review work would be automated. The concept of “living” systematic reviews is already in exploratory development in many research groups including the Cochrane collaboration.³⁷ This approach, if combined with greater reporting transparency³⁸ could help provide a solid basis for a step change in collaborative research gains in the years ahead.

There is an urgent global unmet need for effective scalable interventions for caregivers of people with dementia. This systematic review highlights many promising RCT designs testing online interventions for caregivers and demonstrates that there is increasing research interest in this field. This work also highlights a call for further high quality research whereby the details of interventions are reported in sufficient detail to allow faithful replication. Further, it is evident that RCT evidence is only part of the current body of evidence: more attention to non-RCT evidence may substantially help future trial designs. Expanding and deepening the scope of future studies to look at aspects of usability and acceptability alongside process evaluations would build further on current knowledge. Further, there is a need to focus on caregiver interventions that specifically target those needs identified by caregivers themselves can potentially provide insight into interventions that will impact the physical and mental health of caregivers. Recognizing that caregiver interventions can and should build on the caregiver's existing strengths and resources and be individualized to meet the needs of each caregiving situation can guide future research designs. As care is now being implemented with a person-centered perspective that includes giving voice to people with dementia, the well-being of the caregivers should also be approached with a similar lens. There is now a call for a concerted and cohesive approach from all stakeholders^{6,11} if we are to realize the full potential of this exciting and emerging field.

References

1. ADL. World Alzheimer Report 2016: Improving healthcare for people living with dementia, 2016.
2. Sousa RM, Ferri CP, Acosta D, et al. Contribution of chronic diseases to disability in elderly people in countries with low and middle incomes: A 10/66 Dementia Research Group population-based survey. *Lancet* 2009;374:1821–1830.
3. ADL. Policy Brief The Global Impact of Dementia 2013–2050. Alzheimer's Disease International, 2013.
4. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialog Clin Neurosci* 2009;11:217–228.
5. WHO. Multisectoral action for a life course approach to healthy ageing: Draft global strategy and plan of action on ageing and health, 2016.
6. Rees G. Global action on dementia. *Aust J Dement Care* 2017;16:4.
7. Mittelman MS, Brodaty H, Wallen AS, et al. A 3-country randomized controlled trial of a psychosocial intervention for caregivers combined with pharmacological treatment for patients with Alzheimer's disease: Effects on caregiver depression. *Am J Geriatr Psychiatry* 2008;16:893–904.
8. Olazarán J, Reisberg B, Clare L, et al. Nonpharmacological therapies in Alzheimer's disease: A systematic review of efficacy. *Dement Geriatr Cogn Disord* 2010;30:161–178.
9. Chien L-Y, Chu H, Guo J-L, et al. Caregiver support groups in patients with dementia: A meta-analysis. *Int J Geriatr Psychiatry* 2011;26:1089–1098.
10. Livingston G, Johnston K, Katona C, et al. Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *Am J Psychiatry* 2005;162:1996–2021.
11. Egan KJ, Pot AM. Encouraging innovation for assistive health technologies in dementia: Barriers, enablers and next steps to be taken. *J Am Med Dir Assoc* 2016;17:357–363.
12. Serafini JD, Damianakis T, Marziali E. Clinical practice standards and ethical issues applied to a virtual group intervention for spousal caregivers of people with Alzheimer's. *Soc Work Health Care* 2007;44:225–243.
13. Winblad B, Amouyel P, Andrieu S, et al. Defeating Alzheimer's disease and other dementias: A priority for European science and society. *Lancet Neurol* 2016;15:455–532.
14. Hedman E, Andersson E, Ljotsson B, et al. Cost effectiveness of internet-based cognitive behaviour therapy and behavioural stress management for severe health anxiety. *BMJ Open* 2016;6:e009327.
15. Lintvedt OK, Griffiths KM, Eisemann M, et al. Evaluating the translation process of an Internet-based self-help intervention for prevention of depression: A cost-effectiveness analysis. *J Med Internet Res* 2013;15:e18.
16. Thompson CA, Spilsbury K, Hall J, et al. Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatr* 2007;7:18.
17. Boots LMM, de Vugt ME, van Knippenberg RJ, et al. A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psychiatry* 2014;29:331–344.
18. Topo P. Technology studies to meet the needs of people with dementia and their caregivers: A literature review. *J Appl Gerontol* 2009;28:5–37.
19. Jackson D, Roberts G, Wu ML, et al. A systematic review of the effect of telephone, internet or combined support for carers of people living with Alzheimer's, vascular or mixed dementia in the community. *Arch Gerontol Geriatr* 2016;66:218–236.
20. Shamseer L, Moher D, Clarke M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: Elaboration and explanation. *BMJ* 2015;349:g7647.
21. Higgins JP, Altman DG, Gotzsche PC, et al. The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ* 2011;343:d5928.
22. Guyatt GH, Oxman AD, Vist GE, et al. GRADE: An emerging consensus on rating quality of evidence and strength of recommendations. *BMJ* 2008;336:924–926.
23. Brennan PF, Moore SM, Smyth KA. The effects of a special computer network on caregivers of persons with Alzheimer's disease. *Nurs Res* 1995;44:166–172.
24. Beauchamp N, Irvine AB, Seeley J, et al. Worksite-based internet multimedia program for family caregivers of persons with dementia. *Gerontologist* 2005;45:793–801.
25. Marziali E, Donahue P. Caring for others: Internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative disease. *Gerontologist* 2006;46:398–403.
26. Kajiyama B, Thompson LW, Eto-Iwase T, et al. Exploring the effectiveness of an internet-based program for reducing caregiver distress using the iCare Stress Management e-Training Program. *Aging Ment Health* 2013;17:544–554.
27. Lai CK, Wong LF, Liu KH, et al. Online and onsite training for family caregivers of people with dementia: Results from a pilot study. *Int J Geriatr Psychiatry* 2013;28:107–108.
28. Blom MM, Zarit SH, Groot Zwaafink RB, et al. Effectiveness of an Internet intervention for family caregivers of people with dementia: Results of a randomized controlled trial. *PLoS One* 2015;10:e0116622.
29. Pot AM. Mastery over dementia: An internet intervention for family caregivers of people with dementia. *Alzheimer Dement* 2015;6:S90.
30. Cristancho-Lacroix V, Wrobel J, Cantegreil-Kallen I, et al. A web-based psychoeducational program for informal caregivers of patients with Alzheimer's disease: A pilot randomized controlled trial. *J Med Internet Res* 2015;17:e117.
31. Hattink B, Meiland F, van der Roest H, et al. Web-based STAR E-learning course increases empathy and understanding in dementia caregivers: Results from a randomized controlled trial in The Netherlands and the United Kingdom. *J Med Internet Res* 2015;17:e241.
32. Gaugler JE, Jutkowitz E, Shippee TP, et al. Consistency of dementia caregiver intervention classification: An evidence-based synthesis. *Int Psychogeriatr* 2017;29:19–30.
33. Richard F, Shima S. Empirical studies on the effectiveness of assistive technology in the care of people with dementia: A systematic review. *J Assist Technol* 2014;8:14–34.
34. Dam AE, de Vugt ME, Klinkenberg IP, et al. A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? *Maturitas* 2016;85:117–130.
35. Barroso J, Sandelowski M, Voils CI. Research results have expiration dates: Ensuring timely systematic reviews. *J Evaluation Clin Pract* 2006;12:454–462.
36. Tsafnat G, Glasziou P, Choong MK, et al. Systematic review automation technologies. *Syst Rev* 2014;3:74.
37. Elliott JH, Turner T, Clavisi O, et al. Living systematic reviews: An emerging opportunity to narrow the evidence-practice gap. *PLoS Med* 2014;11:e1001603.
38. Proudfoot J, Klein B, Barak A, et al. Establishing guidelines for executing and reporting Internet intervention research. *Cogn Behav Ther* 2011;40:82–97.

Appendix 1. References of non-RCT studies identified

1. Austrom MG, Geros KN, Hemmerlein K, et al. Use of a multiparty web based videoconference support group for family caregivers: Innovative practice. *Dement Int J Soc Res Pract* 2015;15:682–690.
2. Boots LMM, de Vugt ME, Withagen HE, et al. Development and initial evaluation of the internet-based self-management intervention 'Partner in Balance' for spousal caregivers of people with early-stage dementia. *Int Psychogeriatr* 2015;27:S120–S121.
3. Bottche M, Klasen M, Knaevelsrud C. An Internet-based intervention for health promotion in family caregivers—Results of a pilot study. *Psychiatrische Praxis* 2013;40:327–331.
4. Chiu T, Marziali E, Colantonio A, et al. Internet-based caregiver support for Chinese Canadians taking care of a family member with Alzheimer disease and related dementia. *Can J Aging* 2009;28:323–336.
5. Eisdorfer C, Czaja SJ, Loewenstein DA, et al. The effect of a family therapy and technology-based intervention on caregiver depression. *Gerontologist* 2003;43:521–531.
6. Finkel S, Czaja SJ, Martinovich Z, et al. E-Care: A telecommunications technology intervention for family caregivers of dementia patients. *Am J Geriatr Psychiatry* 2007;15:443–448.
7. Gaugler JE, Hobday JV, Robbins JC, Barclay MP. CARES((R)) Dementia Care for Families: Effects of Online, Psychoeducational Training on Knowledge of Person-Centered Care and Satisfaction. *J Gerontol Nurs* 2015;41:18–24.
8. Glueckauf RL, Ketterson TU, Loomis JS, Dages P. Online support and education for dementia caregivers: Overview, utilization, and initial program evaluation. *Telemed J E Health* 2005;10:223–10232.
9. Griffiths PC, Whitney MK, Kovaleva M, Hepburn K. Development and implementation of tele-savvy for dementia caregivers: A Department of Veterans Affairs clinical demonstration project. *Gerontologist* 2016;56:145–154.
10. Kelly K. Link2Care: Internet-based information and support for caregivers. *Generations* 2003;27:87–88.
11. Kwok T, Au A, Wong B, et al. Effectiveness of online cognitive behavioral therapy on family caregivers of people with dementia. *Clin Interv Aging* 2014;9:631–636.
12. Lewis ML, Hobday JV, Hepburn KW. Internet-based program for dementia caregivers. *Am J Alzheimers Dis Other Dement* 2010;25:674–679.
13. Magnusson L, Hanson E, Nolan M. The impact of information and communication technology on family carers of older people and professionals in Sweden. *Ageing Soc* 2005;25:693–713.
14. Marziali E, Garcia LJ. Dementia caregivers' responses to 2 Internet-based intervention programs. *Am J Alzheimers Dis Other Dement* 2011;26:36–43.
15. McKechnie V, Barker C, Stott J. The effectiveness of an Internet support forum for carers of people with dementia: A pre-post cohort study. *J Med Internet Res* 2014;16:e68.
16. O'Connor MF, Arizmendi BJ, Kaszniak AW. Virtually supportive: A feasibility pilot study of an online support group for dementia caregivers in a 3D virtual environment. *J Aging Stud* 2014;30:87–93.
17. Pagan-Ortiz ME, Cortes DE, Rudloff N, et al. Use of an online community to provide support to caregivers of people with dementia. *J Gerontol Soc Work* 2014;57:694–709.
18. Rosen J, Mittal V, Mulsant BH, et al. Educating the families of nursing home residents: A pilot study using a computer-based system. *J Am Med Dir Assoc* 2003;4:128–134.
19. Schaller S, Marinova-Schmidt V, Gobin J, et al. Tailored e-Health services for the dementia care setting: A pilot study of 'eHealthMonitor'. *BMC Med Inform Decis Mak* 2015;15:58.
20. Torkamani M, McDonald L, Saez Aguayo I, et al. A randomized controlled pilot study to evaluate a technology platform for the assisted living of people with dementia and their carers. *J Alzheimers Dis* 2014;41:515–523.
21. Torp S, Hanson E, Hauge S, et al. A pilot study of how information and communication technology may contribute to health promotion among elderly spousal carers in Norway. *Health Soc Care Commun* 2008;16:75–85.
22. van der Roest HG, Meiland FJM, Jonker C, Drees RM. User evaluation of the DEMentia-specific Digital Interactive Social Chart (DEM-DISC). A pilot study among informal carers on its impact, user friendliness and, usefulness. *Aging Mental Health* 2010;14:461–470.
23. Vehviläinen L, Zielstorff RD, Gertman P, et al. Alzheimer's Caregiver Internet Support System (ACISS): Evaluating the feasibility and effectiveness of supporting family caregivers virtually. *Proc AMIA Symp* 2002:1185.